Chapter 6

A Palliative Care Project: specialized GP advisors provide telephone support to fellow GPs

A report of the Groningen consultation project (2000-2003)

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Introduction

Background

In 1998 the Dutch government initiated a national programme for the further development and improvement of palliative care. Six Centres for the Development of palliative care (COPZ) were established to advance the training, research and opportunities for consultation.

The COPZ Groningen and the Comprehensive Cancer Centre for North Netherlands (IKN) set a primary goal of supporting general practitioners (GPs) in providing palliative care, since the GP was the main care provider for the majority of patients who died of cancer (61% of patients in the region died at home).(1) In 1999 there was just one 'low-care' hospice in the region (in Groningen), in addition to facilities for terminal patients in nursing homes and retirement homes. However, the last two facilities did not offer specifically palliative care and there were no official palliative-care specialists (nurses or doctors) in the region. By 2003 several facilities had been added (hospices in Sneek, Harlingen and Leeuwarden, palliative departments in Zwolle).

Characteristics of care
The region served by the IKN is a largely rural area of 2.1 million inhabitants with 17 hospitals including one teaching hospital, and about 1000 GPs (see figure 6.1). Each year in this region, about 5500 patients die of cancer.(2) Terminally ill patients, which also includes patients with such diseases as heart failure, neurological disorders or COPD, spend most of this period at home, regardless of the actual place of death. Contact with the GP is often more intensive than in other situations and the organisation of care at-home is different compared to the intramural setting. The GP provides continuity of care, including bereavement care, and is used to a holistic approach of the patient and the informal caregivers. There are usually opportunities at home for nursing care at home as well as physiotherapy, occupational therapy, and psychological and other forms of care. The majority of GPs consider palliative care a valuable and challenging, but sometimes difficult, element of their work.(3,4)

Patients
Most patients with cancer wish to die at home.(5,6) Many patients are not afraid to die but are concerned about untreatable symptoms at the end of their lives.(7) They would like to keep control.(8) Continuity of care is of great importance to these patients, including out of hours care.(9-11)

In the four years of this project (2000-2003), the system for primary care changed from small-scale GP practices to large-scale GP 'on call centres'. Many GPs are personally reachable out of hours in the event of a crisis for the patient or informal care-giver.(12)

Design of the consultation project
The COPZ Groningen and IKN decided to hire several experienced GPs working in the region as advisers (GP for at least five years, working one day a week for IKN in addition to their own practice). These GPs took a diploma course in palliative medicine. Since the NHG Palliative Care training did not exist yet, the GPs received their 'Diploma in Palliative Medicine' from Cardiff University, UK. The reason for choosing a GP and not an oncologist or anaesthesiologist as an

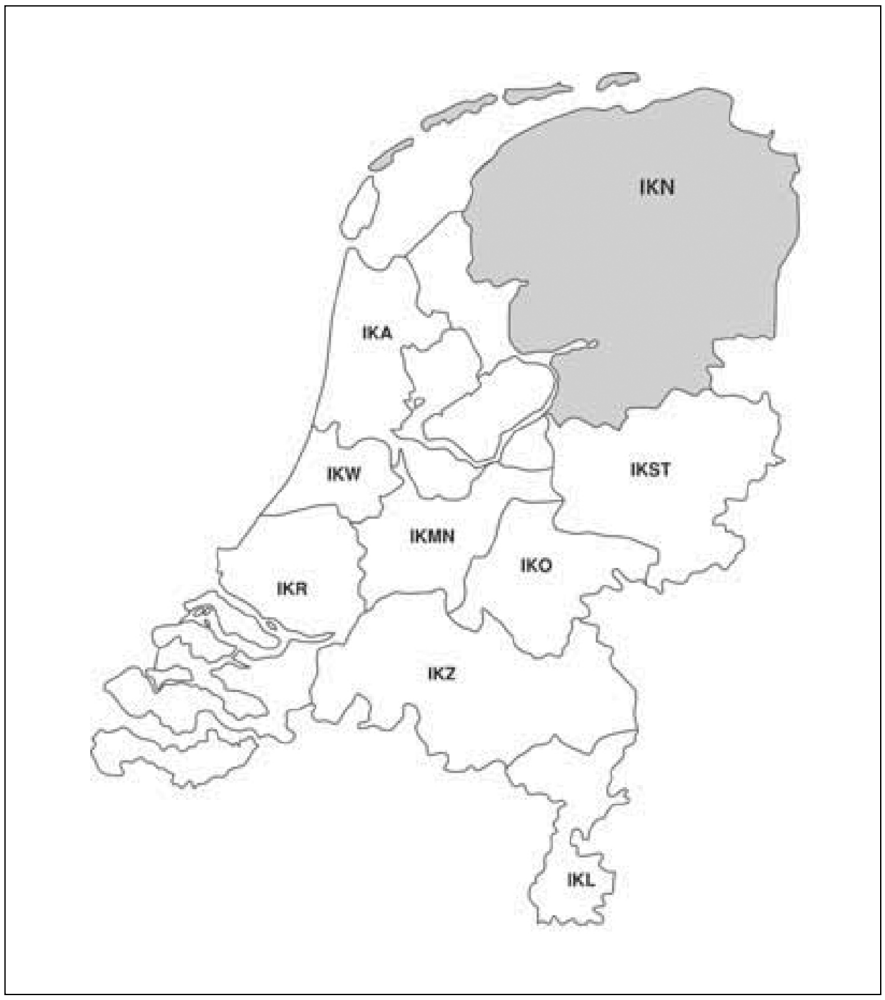

Figure 6.1 Area covered by the IKN (shaded)

adviser was that the GP adviser works in the same extramural conditions as the GP needing advice.(13,14)

In September 1999, four Palliative Care GP advisers were hired for the provinces of Groningen, Friesland, Drenthe and northern Overijssel. The four functioned as a team and discussed in an open atmosphere about the questions and problems put before them, also asking specialists for advice.

To make consultation as quick and efficient as possible GPs in the region could telephone the advisers directly. The advisers would give advice instantly or as soon thereafter as possible. Given that GP care is available 7x24 hours, the advisers were also on call 7x24. In difficult situations, at the advisee's request the adviser sometimes gave a bedside consultation.

The project was made known to local GPs through a specially developed continuing-education programme in pain management and the use of subcutaneous medication. The GP advisor together with the specialized nurse offered this program to every GP group practice in the region. Within two years this programme was being given to nearly every practice. Visiting cards with the telephone numbers were left. These numbers were also published in information leaflets for GPs, on the IKN website and in the guidelines published by the IKN. This start-up phase was evaluated after a year and a half.(15)

Purpose of the study
In this study, we examined how many recommendations were given, by whom and for whom, what problems were addressed, whether the recommendations were followed and whether the consulting GP thought the advices had improved the quality of the palliative care.

Method
We developed a registration and evaluation form for the project using national registration requirements, adding our own questions and practical requirements. The GP advisor recorded the name and address of the GP asking advice, information about the patient (age, sex, residence, diagnosis, medication, prognosis and therapy, care from family/friends, home care and functional status), the initial question, questions raised during the conversation (open questions and in categories) and the advice given.

The patient's functional status was scored using the 'Eastern Cooperative Oncology Group performance status' (ECOG score), ranging from 1 (not limited) to 4 (completely dependent).(16)

The advisers recorded every consultation immediately onto the form, or did so later on the basis of their notes. Any subsequent request for advice was treated as a new consultation if it involved a new problem. If more contacts were needed to solve the same problem, they counted as multiple contacts within one consultation. Fifteen months after the start of the project, the forms were modified in a few points (number of occasions of contact within one consultation, itemizing of symptoms).

Two to six weeks after the consultation, the IKN sent an evaluation form to the advisee GP, with questions about themselves (position, age, sex, urban or rural practice, number of years in practice, solo or group practice, part-time or full-time) and how he or she had heard about the opportunity to use these advisers. We also asked GPs to evaluate the advices: how had the adviser addressed the question, was the advice followed, what value did it have for the patient, had it influenced the quality of the palliative care? The respondent could indicate whether the advice had helped for twelve problem areas, using a five-point scale. We also asked for any points for improvement.

Staff at IKN entered all registration and evaluation data (partly computerised) in the database (SPSS version 11.5). A non-response study was not done.

Results

The consultations

The number of consultations rose from 120 in the first year to 574 in the fourth year (see table 6.1). Of the total of 1385 consultations, 1137 (82%) were from GPs (including GPs in training and locums) and 193 (14%) by others, such as nurses and pharmacists. A filled-in form was lacking for 55 consultations (4%). The GP-advisers gave advice to 859 individual caregivers (identification was lacking in 19 cases). They gave more than one advice (between 2 and 29) to 223 (26%) caregivers. From these data we can extrapolate that about 725 different GPs made use of the opportunity for consultation.

	2000	2001	2002	2003
Total	120	288	403	574
To GPs	95	219	338	485
To others	17	60	53	62
unknown/lacking	8	9	12	27

Table 6.1 Number of consultations per year

Out of the total, 82% of consultations were one-time. For 12%, there were 2 contacts, for 3% 3 and for 2.5% more than 3 (between 4 and 9). For 1056 conversations (76%), the advisers noted the date and time. The number of calls out of hours (10%) and at the weekend and on holidays (5%) remained constant during the period of study. The average conversation lasted 15 minutes (between 5 and 60 minutes).

Characteristics of the patients

The average age of the patients was 62 years (distribution 0-100 years, median 64 years) (see table 6.2). Male patients were slightly in the majority. Of the patients, 92% were at home, 4% in a nursing home and 4% in a hospice. Ninety-five percent of the patients received care from family/friends/neighbours; a slightly rising percentage (from 76% in 2000 to 81% in 2003) had professional nursing care at home. Forty-eight percent of the patients were 'completely bedridden and dependent' (ECOG score 4), 36% of the patients spent more than half the time in a chair or in bed (ECOG score 3). The average life expectancy of the patient at the time of consultation was several days (32%) or weeks (39%) (see table 6.3).

Age group	2000	2001	2002	2003
0-18 years	2	4	12	11
19-49 years	26	27	53	61
50-64 years	35	100	102	184
65-79 years	42	107	137	181
80 years and older	10	21	44	56
data lacking	5	29	55	81

Table 6.2 Age distribution of the patients

	2000	2001	2002	2003
hours	1	5	10	11
days	30	92	128	200
weeks	53	114	161	217
months	23	29	39	60
years	1	5	6	8
data lacking	12	43	59	78

Table 6.3 Estimated prognosis of the patient

Nature of the problems

Most consultations involved patients with lung cancer (15%), intestinal cancer (12%), breast cancer (8%) or other terminal conditions (13%). A diagnosis was lacking in 23% of the records (see table 6.4).

The initial question involved physical symptoms in most cases (70%); 13% of the conversations were about pharmacotherapeutic policy and 17% about other problems. Ultimately, fewer than half of the consultations turned out to be limited to one problem (see table 6.5); often a conversation with the consultant raised a larger number of problems. The total number of initial questions was 1855 (average 1.3 problems per conversation), after discussion there were an additional 838 problems, on average 1.9 per conversation. The number of physical problems remained about the same during the discussion, but often other problems came up (see table 6.6). The most common physical symptoms were pain (39%), nausea and vomiting (20%), delirium (10%) and dyspnoea (8%).

The incidence of symptoms about which advice was asked varied by the type of cancer. Pain was more common with lung cancer, skin cancer and prostate cancer; nausea and vomiting with ovarian cancer, stomach cancer and colorectal tumours; delirium with kidney cancer, lung cancer and prostate cancer; dyspnoea with lung cancer, malignant lymphoma and breast cancer.

Type cancer	Total number	Type cancer	Total number
Lung	208	Ovary	41
Other known origin/cause	185	Skin	33
Colorectal	170	Head/neck	27
Breast	111	Bladder	24
Prostate	85	Lymphoma	22
Stomach	72	Endometrium	7
Oesophagus	42	Unknown/data lacking	317
Kidney	41		

Table 6.4 Number of consultations per diagnosis

Number of problems	At initial question	After delineation
Four problems	0%	10%
Three problems	6%	16%
Two problems	22%	30%
One problem	72%	44%
	100%	100%

Table 6.5 Increase in number of problems after delineating the question

Problem area	Number at Initial question	Number after delineation
Pain	509	501
Other physical symptoms	794	859
Pharmacotherapy	238	476
Psychological problems	68	116
Existential questions	20	40
Social problems	25	56
Medical-technical problems	70	160
Organisational problems	25	87
Communication problems	23	78
Planning problems	30	103
Need for confirmation	31	142
Problem of the physician	22	65

Table 6.6 Content of the consultations

Evaluation by the GPs

Out of a total of 1389 evaluation forms sent by the IKN to those who had asked for advice, 947 (68%) were returned completed. Ninety-one percent of respondents were GPs, who had worked an average of 12.9 years in practice (ranging from less than 1 year to more than 35 years). They were representative of the GP population in the area for age, sex, place of work (urban vs. rural), type of practice and full-time or part-time work. Forty-eight percent of responding GPs had met the GP adviser through the continuing education programme.

The response to the question: 'Did you follow the recommendations of the GP-adviser?' was affirmative in 85% of the cases, 11% had partly followed the advice and 4% had not. Nearly the same percentages applied to the value that the advice had for the patient and for the quality of the palliative care: the respondents considered 86% of the advices valuable in this regard as well.

This favourable evaluation also applied to the entire spectrum of problems: The scores were 4 and 5 on all the five-point scales.

Discussion

This is the first longitudinal, descriptive study of telephone consultation about palliative care, administered to GPs by fellow GPs.

The increase in the number of consultations during the course of the project suggests that this service meets a need. Over 700 GPs, or two-thirds of all the GPs in the region, made use of it.

In many cases, consultation took place shortly before death: in 32% of the cases the prognosis was estimated to be days. In a similar study with consultation teams, only 13% of the patients had such a short prognosis.(17) Evidently GPs often have a need for consultation shortly before the death of the patient, and the threshold for consulting a fellow GP is not high.

The initial question usually involved the control of physical symptoms. This was also the case in comparable projects in the Netherlands (18,19) and England.(20) Making an inventory of the problems during the consultation, however, often brought more problems to light than the GP requesting advice indicated at first. This shows the additional value of direct communication: this would probably not have happened if the GP had gone on the Internet looking for a solution of the physical problem. While providing palliative care, difficult situations can come up for the treating physician.(13,21) If the physician him- or herself has a problem or needs confirmation, this can only be addressed in a conversation.

The advices given by the GP-advisers were followed in 85% of the cases and 86% of those who had asked advice felt that it had improved the

quality of care. In the study with consultation teams this percentage was 65%.(17) Evidently, consulting a fellow GP is a better fit for the GP. It does not ignore, however, the fact that discussion in a team may be more effective for an optimum palliative treatment. However, this could primarily be true for intramural patients and less so in a home situation.(22) Of course, it remains important that caregivers coordinate among themselves.(23)

The opportunity to consult at the patient's bedside was kept open but not propagated in our project. Each year there were five to ten such consultations, always at the explicite request of the treating GP.

Limitations of the study

Unfortunately, the GPs were not asked about the influence of the advices on the place of death. In a number of cases, the consultation could have prevented the patient being hospitalised. In a retrospective Dutch study, half of terminal patients were still admitted to hospital, often less than a week before death.(18) This possible effect is certainly worth a follow-up study.

Given the rural character of the region, our study population was not representative of the Dutch situation. Although 95% of our patients had care from the 'network' of family/friends and neighbours, this could be quite different in other regions, with all the consequences for the possibility of staying at home in the last phase of life. The fact that in 2003 informal caregivers provided all the care for 19% of the patients, without help from home-care agencies, may be locally based and may have risen from a need to manage independently.

The opportunity to consult a GP adviser has the ultimate goal of improving the quality of palliative care at bedside. These effects should be measured at the level of the patient. In our set-up, however, the advisees selected themselves because of their need for advice, and a study with that bias at patient level would be useless.(24,25) Thus we cannot answer the question, objectively seen, to what extent our project has contributed to improving the quality of palliative care at home.

There was no possibility within our project for additional research, such as the non-response to the evaluation, or to obtain the missing data. The GP-adviser did this work in between all his or her regular tasks, which rendered the records not always complete.

The future

Much has changed in the palliative field since our project started in 2000. Dying with dignity at home is only possible under particular circumstances: there must

be sufficiently supported care from the patient's informal network, good control of the patient's symptoms and dedicated GPs with sufficient knowledge and skills in palliative medicine; GPs who if necessary can consult colleagues with particular expertise.(26,27) Nursing care available at short notice is essential in providing care at home. Applying market forces in medical care might have negative effects and result in a reduced quality of care.

It emerged from our research that in continuing-education attention must be paid to familiarity with and opportunities for symptom control – in general and in the home situation. Ultimately, all the GPs in the region must be motivated to make use of consultation in palliative care when it is needed. It is of great importance that there is coordination between primary and secondary care. This applies to guidelines on symptom treatment and to information about transfer of the patient.

One weak point in the current organisational structure is that only one adviser has been hired per region. If one or two advisers are absent, it will become difficult to continue the consultant's position in the current setup. Further research is needed into an optimum working method for palliative-care GP advisers (for example, directly reachable by telephone or not, in a team or individually, as employees or not) and further evaluation of their significance for a dignified death at home – both in controling symptoms and in supporting colleagues, potentially avoiding hospitalisation – is indicated.

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Summary

Telephone consultation advice about management of nausea and vomiting was given by GP-advisors to GPs seeking advice for their care of patients dying at home. Advice given resulted in marked changes in management (type of medication and route of administration) and a positive evaluation about the consultation service by those using it.